Parents as Practitioners of Preterm Care

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Paediatrician-in-Chief,
Mount Sinai Hospital;
Objectives

- Background of Family Integrated Care
- Family Integrated Care
  - Core concepts
  - Objectives
  - Development of program
- Pilot Study results
- Multi-center cluster randomized controlled trial
Family Centered Care - current practice

• Arrange activities for family convenience
• Professionals provide care, not family
• Family members are encouraged to visit, and to participate in baby’s care in an incremental but unstructured way
• NICU is an open concept, with limited privacy for family members
Family Centred Care from outside to ...
Inside…..
Levin Study (Birth 1994) - Humane Care

Compared 84 care by parent with 72 care by nurses babies in the NICU

<table>
<thead>
<tr>
<th>Weight gain (g)</th>
<th>Maternal Care</th>
<th>Nurse Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 days</td>
<td>332 ± 20</td>
<td>235 ± 30</td>
</tr>
<tr>
<td>30 days</td>
<td>769</td>
<td>490</td>
</tr>
</tbody>
</table>

Results =
- 30% reduction in NI
- 20% reduction in LOS
- 50% reduction in nurse utilization
- improved parent/staff satisfaction
How can we adapt this philosophy of humane care for Canada?

Family Integrated Care
Family Integrated Care Program
Objectives

• To determine whether Family Integrated Care can be adopted in Canada
• Formative study of how to develop a Family Integrated Care Model for Canada
• Pilot study of feasibility and safety
• Conduct multi-center cluster RCT
The Family Integrated Care Steering Committee:

- Veteran Parents (x3)  - Nurses (x3)  - Study Coordinator

- Physicians (x2)  - Allied Health (x2)
Consultation & Development

- Veteran parents were invited in at the very beginning as co-chairs and key team members to translate this idea to practice
- Consent
- Literature review
- Protocol development
- Visioning a “day in the life of”
- Anticipated problems
- Legal and liability
- Ethics
Pillars of Family Integrated Care

• How does our project fit into the Theoretical Framework of Patient and Family Centered Care?

• Core principles of Family Centered Care interwoven in Family Integrated Care
Pillars of Family Integrated Care 1: Parents are part of the care team

- People are treated with respect and dignity
- The family are invited to participate to the best of their ability and supported to do so
Pillars of Family Integrated care 2:
Parental Education is a requirement

- Families build on their strengths by participating in experiences that enhance control and independence
- Mothers collaborate in their infant’s care
- Parental learning is facilitated
Pillars of Family Integrated care 3: Parents are integrated into all aspects of care

- Health professionals share complete information with patients and families
- Parents participate on rounds
- Nurses are provided with tools & education to enable families to be part of the team
Pillars of Family Integrated care 4:
The care team must support parents

• Collaboration occurs in policy and program development, professional education and delivery of care
• Infant holding and mothers at their baby’s bedside is supported by unit policies, physical and environmental supports
• The entire care team supports model of care
What is Family Integrated Care?

1. Change in paradigm of care-giving in the NICU
2. Parents are an integral part of the care team and are partners with nurses and the medical team
3. Nurses are teachers and consultants to parents
4. Parents assume most of the care for baby, except for IV, medication and tests
5. Parents gain confidence, knowledge and control
Pre-pilot: Veteran Parent involvement

• Formal structure
  - Steering committee
  - Workgroups with a parent lead in each group

• Build alliances: representation from all disciplines, seeking buy in from nursing and medical staff

• Collaborative & Responsive: do what you can with what you have
Project Parent Training

• Curriculum guided by adult learning principles

• Cyclical education program developed collaboratively
  - veteran parents, parent resource nurse and subject experts

• Bedside training
  - guided by bedside nurse
  - tracked with skills checklists
Parental Involvement

- Uninvolved parent
  - None
    - Views infant comfort as nurse or doctor role only
  - Be informed
  - Be present
  - Provide comfort
    - Touch
    - Voice
    - Specific comforting techniques
  - Informant for NICU staff
  - Active decision maker
  - Advocate for infant
    - Primary responsibility in partnership with clinical care team
- Involved parent
Pilot Project

- Pilot start date: March, 2011
- Prospective matched case control
- Informed consent
- Expected length of study: 12 months
- Number of patients needed: 40 patients, 80 matched controls (GA, wt, sex)

Location
- 4 bed spaces reserved in Level II TLC area

Time Commitment for Parents
- Minimum 8 hours each day - during day

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<th>Inclusion Criteria:</th>
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Outcomes

- Primary: Weight gain
- Secondary: mortality and morbidity (NEC, infection, BPD, IVH, ROP), LOS
- Sample size: 20 each group, power 1.0 to detect expected 200 g weight gain
Nurse Recruitment

- Information pamphlet
- Information sessions
- Active recruitment
- 40 volunteers

TLC RESEARCH PROJECT:
An exciting new
TEACHING, LEARNING, CARING
initiative in our Valentine NICU

NICU Nurses play an essential role in an infant’s circle of care.
You make parenting possible in the NICU. You know about the unique needs of each baby and you can teach parents to understand and help their babies. As parents learn, they feel more confident caring. The babies teach us all. We can all teach, learn and care together. This is the TLC project in a nutshell.

We envision this research project as epitomizing the true nature of family-centred care in which families and nurses work together to ensure the best possible outcome for the baby and the family. Working together may help babies gain weight faster, go home sooner and may aid in their development. It may also boost parental confidence which will prepare them for life at home with their babies.

DETAILS:
- We need 30 NICU bedside nurses to participate
- Nurses should have 1+ years of NICU experience
- Training includes 1 four-hour workshop and on-going support
- TLC Research Project should be completed within 6 months from start date
- Training and Research Project launch Winter 2011

Co-Investigators are Dr. Shoo Lee and Dr. Karel O’Brien
To learn more or to join the TLC Bedside Nursing Team, please contact:
Tenzin Dicky, TLC Project Nurse @ tdicky@mtsain.on.ca

MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex
Supports for Parents

- Bedroom, bathroom, lounge, kitchen, computer facilities
- Sleeper lounge chairs in NICU
- Breast milk pumping room
- Free parking
- Meals
- No decrease in nursing ratio
- Parent buddy volunteers
- Access to psychologist, therapist if needed
What is different for Project Parents?

- Parents providing care for their infant
- Parent charting
- Parents presenting on rounds
- Parents directing their learning/skill acquisition
What is different for Nurses?

- Increased mentoring of parents
- Signing off on parental acquisition of skills
- Greater interaction with parents at the bedside/psychological support etc
- Sharing rounds with the parents
- Sharing charting with the parents
The pilot families: who were they?

- 42 mothers (4 sets of twins)
- 17 (40%) have other children at home
- 22 (55%) were Canadian born; 11 lived in Canada >10 years
- All had at least grade 10 high school education;
- 27 (71%) were employed outside the home
- Varied in age from 23-35 years (mean 33 years)
Status report: the infants

- 46 infants enrolled
- Complete data on 42 (3 discharged within a week of enrolment, 1 unstable)
- Of the 42 completed, 17 were transferred to a level 2 site prior to discharge home
- 25 were discharged home directly from MSH
- Matched controls were identified for 31 enrolled infants
# Infant Characteristics

<table>
<thead>
<tr>
<th>Infant Characteristics</th>
<th>FICare Group (n=31)</th>
<th>Control Group (n=62)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gestational age mean (sd)</td>
<td>27.3(2.3)</td>
<td>27.7(2.6)</td>
<td>0.31</td>
</tr>
<tr>
<td>Birth Weight mean (sd)</td>
<td>1106 (419)</td>
<td>1061(389)</td>
<td>0.11</td>
</tr>
<tr>
<td>SNAP 11 score(&gt;20) n (%)</td>
<td>6 (19.4)</td>
<td>13(21.0)</td>
<td>0.85</td>
</tr>
<tr>
<td>Age at enrolment days mean (sd)</td>
<td>30.2(20.3)</td>
<td>30.2(20.3)</td>
<td>NS</td>
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</table>
## Outcomes

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<th>Infant Outcomes</th>
<th>FICare group Mean (sd)</th>
<th>Controls Mean (sd)</th>
<th>P-value</th>
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<tr>
<td>Zwt21-Zwt 1 Discharge weight gain</td>
<td>0.61(0.44) 25%</td>
<td>0.49(0.41)</td>
<td>0.26</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>21 day wt gain (g/kg/day)</td>
<td>21.6 (6.4) 9%</td>
<td>20.3 (6.6)</td>
<td>0.48</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>85%</td>
<td>42%</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Nosocomial infection</td>
<td>0</td>
<td>6(9.7%)</td>
<td>0.59</td>
</tr>
<tr>
<td>ROP</td>
<td>0</td>
<td>8(14.3%)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Incident reports Per 1000 patient days</td>
<td>0.84 25%</td>
<td>1.15</td>
<td>0.73</td>
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## Parental Stress (PSS-NICU)

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<th>PSS on admission</th>
<th>PSS at 35 weeks</th>
<th>P-value of difference</th>
</tr>
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<tr>
<td><strong>Patients</strong></td>
<td>3.10 (0.72)</td>
<td>2.34 (0.73)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Controls</strong></td>
<td>2.83 (0.85)</td>
<td>3.00 (0.77)</td>
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</table>
“It was so overwhelming when we first got into the NICU. We had no idea how to care for babies and the nurses educated us on everything that we needed to do on a daily basis. By the time we got to our Level 2 hospital we had done everything from bathing our babies to just being comfortable with breastfeeding and giving medications. It just got us closer to understanding medical issues that were going on with our babies. In fact we did rounds every day. It was I think an amazing programme.”

Michelle mother of twins
The Celebration
The FiCare Multi-center Cluster RCT

- Prospective multi-centred cluster RCT
- 2 year trial funded by CIHR
- 20 Canadian + 10 Australia/New Zealand NICUs
- N = 675 patients/arm
- <33 weeks GA

Eligibility Criteria:

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<td>• A primary caregiver parent, willing and able to commit to spending 8 hours per day with their baby between the hours of 0700 and 2000.</td>
<td>• Critical illness (unlikely to survive)</td>
</tr>
<tr>
<td>• Parental consent</td>
<td>• On high level of respiratory support</td>
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The FiCare Multi-center Cluster RCT

- **Outcomes:**
  - Primary = weight gain
  - Secondary = breast feeding, clinical outcomes, safety, satisfaction/stress/anxiety, resource use

- **Assumptions:** 50% enrollment, 10% drop out

- **Power:** $0.80$, $p = 0.05$, ICC = 0.01

- **Sample size of** $n=675$ **patients will give power to detect:**
  - 10% difference in weight gain velocity &
  - 30% difference in infection rates
The Community Hospital Trial

- Majority of babies admitted to Community Level 2 NICUs
- Question - can FiCare work in Level 2 NICUs
- Pilot project funded by MOHLTC
- 4 Ontario + 9 Alberta hospitals - all babies
- Parent teaching emphasize different things
- Modular virtual training for nurses
- Primary Outcome: Weight gain
- Secondary Outcome: LOS, parental stress, infection, critical incident reports
Other Trials

- FiCARE China
- FiCARE USA
- FiCARE UK
- FiCARE Africa
- NAS Trial
- Surgical and complex patients trial
- Other areas of pediatrics?
- Other areas of health care?
Getting buy-in lectures to parents

Getting buy-in lectures to staffs & nurses

[Images of lectures to parents and staffs & nurses]
Both Moms and Babies are doing great!
Future Neonatal Intensive Care Unit
Principles to Ponder

- Bring families back into care process
- Empower families
- Treat the family as a single care unit
Family Integrated Care - Dawn of a New Era

- With acknowledgements:
  - Canadian Neonatal Network
  - Canadian Institutes of Health Research
  - Ontario Ministry of Health & Long Term Care
  - Participating Institutions